



Supportive Care Coalition

Pursuing Excellence
in Palliative Care

Established 1994

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Ascension Health
St. Louis, MO

Bon Secours Richmond
Richmond, VA

Catholic Health Association
of the United States
St. Louis, MO

Catholic Health Initiatives
Denver, CO

Catholic Healthcare Partners
Cincinnati, OH

CHRISTUS Health
Irving, TX

Covenant Health Systems
Lexington, MA

Our Lady of the Lake Regional Medical
Center, Baton Rouge, LA
and
Our Lady of Lourdes Regional
Medical Center, Lafayette, LA

PeaceHealth
Bellevue, WA

Provena Health
Mokena, IL

Providence Health & Services
Seattle, WA

Sisters of Charity of Leavenworth Health
System, Leavenworth, KS

SSM Health Care
St. Louis, MO

Trinity Health
Novi, MI

August 22, 2006

Patricia Maryland, PhD
Chair, Citizens' Health Care Working Group
7201 Wisconsin Ave.
Suite 575
Bethesda, MD 20814

Dear Dr. Maryland,

On behalf of **Supportive Care Coalition: Pursuing Excellence in Palliative Care**, our board and member Catholic health care systems and organizations, we thank you and the members of the Citizens' Health Care Working Group for your leadership and for the opportunity to comment on the Interim Recommendations focused on improving health care for everyone in the United States. The Supportive Care Coalition is currently comprised of 15 Catholic health care systems and organizations that provide services throughout the United States. Its mission is to advance excellence in palliative care through knowledge transfer, advocacy and partnerships.

The Supportive Care Coalition envisions "a society in which all persons living with or affected by a chronic or life threatening condition receive compassionate, holistic, coordinated care. This will include relief of pain, suffering and other symptoms from the time of diagnosis throughout the process of living and dying. Such excellent care will be provided according to need, respecting the values and goals of individuals, their families and other loved ones. It will assist them to live fully in community and will support survivors in their bereavement." The inclusion of palliative and hospice care in your recommendations furthers that vision.

We would like to stress in particular that we agree with every one of the Values and Principles articulated in the document. Articulating these values and principles is essential for an appropriate interpretation and implementation of the specific recommendations. Our specific comments are on the recommendations as they appear in the **July 18 updated version**.

Recommendation: Guarantee financial protection against very high health care costs. We support this recommendation and believe that access to affordable health care is essential for protecting human dignity, especially in the most vulnerable, including those living with

life-threatening illness or who are in the last phases of their life. The escalating problem of the uninsured has reached crisis proportion calling for action. Health care is an essential building block for a just and free society.

Recommendation: Support integrated community health networks. We support this recommendation and, in particular, the four action strategies identified under this general recommendation. We concur with the concerns expressed in the community meetings, especially by low-income, uninsured and underinsured persons, about lack of primary care providers; inability to access specialty care; and difficulties in navigating a complicated system, especially for those with chronic conditions. These concerns are consistent with our observations regarding the many barriers to quality palliative care.

Recommendation: Promote efforts to improve quality of care and efficiency.

We concur with this recommendation. However, in respect to the specific recommendations, it is our hope that efforts to promote health education, disease prevention and health promotion not be misconstrued by policy makers, payers or providers to suggest that those individuals living with chronic conditions are solely responsible for their own illness and therefore are not “worthy” of the care they need in order to increase the quality of their lives. While individuals should be encouraged and be given incentives to promote their own health and to take responsibility for it, there are underlying inheritance factors, socio-economic, community, educational and family influences that must be considered, and for which individuals cannot be held accountable on their own. Individuals are *social beings*, and cannot be isolated from the communities and family structures and systems in which they live and work.

Integrated health care systems have the capacity to coordinate care across the continuum. They should include palliative care and end of life services within the continuum. The art and science of palliative care has advanced especially over the past 10 years and research has indicated that it has had a positive impact on quality of care, quality of life, and reduction of health care costs during the last phases of life. Clinical Practice Guidelines for Quality Palliative Care have been developed through the National Consensus Project (www.nationalconsensusproject.org) and the National Quality Forum has released a complementary document entitled “A National Framework for Palliative and Hospice Care Quality Measurement and Reporting” (www.qualityforum.org). These guidelines were established through a broad professional consensus and should be taken into consideration by policy makers and payers.

Recommendation: Fundamentally restructure the way that palliative care, hospice care and other end-of-life services are financed and provided, so that people living with advanced incurable conditions have increased access to these services in the environment they choose. We support this recommendation. Palliative care services should be comprehensive, life-affirming, flexible and coordinated, reaching across the continuum. Currently, the Medicare hospice benefit is available only for those with a prognosis of six months or less, and many progressively and chronically ill people cannot get supportive health and community services when needed. While we acknowledge that people living in the final phase of their lives have special needs that must be addressed, it is inadequate to focus solely on the dying phase because failure to implement supportive care interventions earlier in the disease process leads to preventable increased pain and suffering. Professional education about palliative care and greater flexibility around how and when

hospice and palliative care services are delivered and reimbursed will go a long way to push palliative care interventions further upstream in the disease process, ensuring that people get the services they need when they need it, without having to forgo other needed services. If palliative care programs are more available, many late hospice referrals could be eliminated.

It is important to include individuals facing critical, advanced, chronic or life-threatening illness as recipients of palliative care from the point of diagnosis through the course of their illness. Such care should be available for both adults and children and delivered in a culturally sensitive manner. A pediatric program model that we call to your attention is the CHI PACC model (Children's Hospice International Program for All-inclusive Care for Children and their families, at <http://www.chionline.org/programs>). The CHI PACC demonstration models in 6 states have been working well.

Likewise, there are innovative palliative care programs directed at the frail elderly.

An example of this is found at

http://www.supportivecarecoalition.org/SupportiveVoice/SV_Vol_11_No_2_Lee.htm

Most elderly struggle with not one but several health conditions, none of which may be serious enough to call attention to their plight; however, together these diseases greatly impact their quality of life. In particular, those living in the community rather than in facilities are at greatest risk for being overlooked for palliative services.

In the discussion of having choices honored in this recommendation, we presume that you are referring to choices for medically *appropriate* care. This would exclude treatments that have no expected benefit, as well as physician-assisted suicide. Where legalized, physician-assisted suicide should not be financed by insurers or the government, and caregivers should never be required to participate. Every effort should be made to address the underlying causes contributing to requests for physician-assisted suicide.

Recommendation: It should be public policy that all Americans have affordable health care. It is our belief that health care is a basic human right, and that everyone should have access to affordable health care, that is, to a defined set of benefits. If health care is a right, there must also be shared responsibility for health and health care in this country – a collaborative effort of the common good, between individuals and corporations, between payers and providers, and between the public and private sectors. We do not hold a position at this time on what would be the preferred payment system. The document's discussion under this recommendation explores this issue thoroughly, and recognizes the many competing considerations that will have to be made.

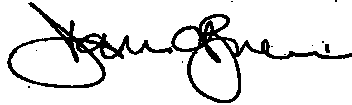
Recommendation: Define a 'core' benefit package for all Americans. We generally concur with this recommendation. However, the definition of health should include "spiritual well-being," acknowledging the interconnection of body, mind and spirit and their impact on health. Health care includes relief of suffering and distress including physical, spiritual and emotional distress. Supporting the spiritual and emotional well-being of persons is consistent with both palliative care and hospice philosophy and should not be misconstrued as promoting or establishing religion. Also important is the interdisciplinary team approach to care of the whole person, and the inclusion of the patient and family as part of the care team. Bereavement services are also a necessary part of supportive care.

The loss of a loved one impacts the health and well-being of survivors and produces a ripple-effect on their communities.

Finally, we concur with the comments provided by the **End-of-Life Nursing Education Consortium** (ELNEC) including “that issues related to end of life/palliative care be woven throughout the entire recommendations, so that both are seen as more ‘mainstream’ and its attributes would become an integral concept of quality health care throughout the life span.” We support the examples provided in the ELNEC recommendations for embedding palliative/end of life care throughout the document.

In closing, we thank you for considering our comments and suggestions. As one of our board members has stated: “The very foundation of health care is conviction that we must do what we can to prevent and relieve the pain and suffering of neighbors and strangers. Insofar as public policy can assist in removing barriers to such care and support seamless, high quality care in institutions, in the community or at home, it should do so. How could we not!” We look forward to your final recommendations and hope that they will result in action soon.

Sincerely,

A handwritten signature in black ink, appearing to read "Dan O'Brien", with a large, stylized loop at the end.

Dan O'Brien, PhD
Chairperson

A handwritten signature in black ink, appearing to read "Karin Dufault SP", with a stylized "SP" at the end.

Karin Dufault, SP, RN, PhD
Executive Director

